

Quatitative systematic review of mental health services from the users' perspective*

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Objective: to identify, based on qualitative systematic literature review, Brazilian national and international publications in mental health area, addressing service's evaluation on their users perspective. Method: a qualitative systematic literature review, which followed PRISMA orientations and criteria. For that, two international platforms that include a significant number of databases were used, with "mental health" and "evaluation" descriptors and 2004 to 2016 period. Results: 4,735 full articles were initially collected, with final eligibility of 137 for integral text reading, of which 44 were included in the final analysis. Research studies on mental health services evaluation with users' participation are present in Brazil, but still in reduced number when compared to countries like England, Australia and USA. Conclusion: in Brazil, as well as in other countries, the ways by which users participate in services evaluations are still a challenge. Mental health service users' protagonist is insufficient. In Brazil, there is also a challenge to structure public services systematic evaluations, incorporating diversity of evaluative methods and stakeholders' participation.

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Revisão sistemática qualitativa sobre avaliações de serviços em saúde mental na perspectiva dos usuários

Objetivo: identificar publicações nacionais brasileiras e internacionais na área de saúde mental sobre avaliação de serviços, destacando as formas de participação dos usuários. Método: trata-se de uma revisão sistemática qualitativa da literatura, que seguiu as orientações do PRISMA e utilizou duas plataformas internacionais que agregam um número significativo de bases de dados, com os descritores (saúde mental e avaliação) no período de 2004 a 2016. Resultados: levantou-se 4.735 artigos completos; tendo elegibilidade final de 137 artigos para leitura integral, sendo 44 incluídos na análise final. Percebe-se que há pesquisas sobre avaliação de serviços de saúde mental com a participação dos usuários no Brasil, mas ainda em número menor em comparação com Inglaterra, Austrália e EUA. Conclusão: a forma de participação dos usuários nas avaliações dos serviços, tanto no Brasil quanto em outros países, ainda é um desafio. Há pouco protagonismo dos usuários. No Brasil, coloca-se o desafio ainda de estruturar avaliações sistemáticas dos serviços públicos, com multiplicidade de métodos avaliativos e envolvendo todos os atores.

Descritores: Avaliação em Saúde; Saúde Mental; Revisão Sistemática; Participação do Paciente.

Revisión sistemática cualitativa sobre evaluación de servicios de salud mental desde la perspectiva de los usuarios

Objetivo: identificar publicaciones nacionales brasileñas e internacionales en el área de salud mental sobre evaluación de servicios, con énfasis en las formas de participación de los usuarios. Método: este estudio es una revisión sistemática cualitativa de la literatura, que siguió las recomendaciones de PRISMA y utilizó dos plataformas internacionales que incluyen un número significativo de bases de datos, con los descriptores (salud mental y evaluación) en el periodo de 2004 a 2016. Resultados: se identificaron 4.735 artículos completos; siendo elegidos 137 para lectura completa, al final, se incluyeron 44 en el análisis. Los resultados sugieren que en Brasil hay investigaciones sobre la evaluación de servicios de salud mental que cuentan con la participación de usuarios, pero el número es menor en comparación con Inglaterra, Australia y Estados Unidos. Conclusión: la forma en que los usuarios participan en las evaluaciones de servicios, tanto en Brasil como en otros países, sigue siendo un desafío, hay poco protagonismo de ellos. Brasil, además, tiene el desafío de estructurar evaluaciones sistemáticas de los servicios públicos, con una multiplicidad de métodos de evaluación que involucren a todos los actores.

Descriptorios: Evaluación en Salud; Salud Mental; Revisión Sistemática; Participación del Paciente.

Introduction

Psychiatric reform projects in different countries emerged in the context of criticism of asylum institutions after World War II. These were criticized for their low therapeutic efficacy, high maintenance costs, the violence with which they treat people and the social exclusion they generate⁽¹⁻²⁾.

This process resulted in initiatives aimed at the humanization of psychiatric hospitals, reflections on the quality of treatment and the creation of mental health services in the community⁽³⁾. In Brazil, this process is called the Brazilian Psychiatric Reform, which encompasses and articulates the technical assistance, political, legal, conceptual and socio-cultural fields⁽⁴⁾.

However, despite almost 30 years of implementing community mental health services in Brazil and 17 years of Law 10,216, which provides for the rights and protection of people with mental disorders, which systematically systematized, organized and implemented services⁽⁵⁻⁶⁾, the country still lacks service evaluation indicators⁽⁷⁾.

There is a shortage of Brazilian studies with mixed methods that describe evaluation and results processes, which contemplate the Psychosocial Care Network (*Rede de Atenção Psicossocial*, RAPS) mainly from the users' perspective⁽⁸⁾. In Brazil, the field of evaluation is incipient in general and mental health has particularities that make consensus around evaluative parameters a constant methodological challenge⁽⁷⁻⁸⁾.

The World Health Organization⁽⁹⁻¹⁰⁾ has produced technical reports and analyzes to support common objectives for sectorial mental health policies, seeking to establish consensus and create indicators. There is a worldwide trend towards the users' incorporation, based on their experience of falling ill and the relationships with the treatment spaces, in the evaluation processes of the services and assistance they have provided.

We understand that the users' participation in evaluations about health services is fundamental for obtaining results that represent them, in addition to influencing public policies that are effective and functional for the group of people served, valuing the knowledge that comes from the lived experience, thinking about ways and strategies to enhance the dialogue⁽¹¹⁾.

Therefore, the current challenge is to evaluate the network of territorial services and the treatment orientation, which values the experience of people in their daily lives and their recovery processes, as the challenge of the new services is to bring the user to the center of the scene of their treatment⁽¹²⁻¹⁴⁾.

Thus, the results found by two studies⁽⁷⁻⁸⁾ suggest that in Brazil, there are few studies that propose to evaluate mental health services from the perspective and with the participation of its users, when compared to the international scenario⁽⁷⁻⁸⁾.

Our interest at this point was to reveal how this phenomenon behaves both on the national and international scene through a qualitative systematic review on the users' participation of mental health services in their evaluation and we raised the following questions:

1. What is the national and international scenario for evaluating mental health services with the participation of the users of the system? and;
2. What is the form of user participation during the process of evaluating mental health services?

The objective of this work was to identify Brazilian and international national publications in the area of mental health, addressing the evaluation of services, highlighting the forms of user participation.

Method

To achieve the objective proposed in this work, we carried out a systematic qualitative review following the organizational guidelines of PRISMA reviews⁽¹⁵⁻¹⁶⁾. The qualitative systematic bibliographic review provides for a synthesis of studies containing objectives, materials and methods that are clearly explained and conducted according to an explicit, reproducible and rigorous method for identifying texts, making a critical assessment and synthesizing relevant studies⁽¹⁷⁾.

We use two international platforms that include a significant number of databases in order to get closer to the largest number of productions in the area.

The first platform to be used was the Virtual Health Library - VHL. The choice of this source is due to its wide and consolidated use in the field of health, especially in Brazil and in most Latin American countries. The keywords used were the following: EVALUATION and MENTAL HEALTH, and the filters: full texts available, country of affiliation, Brazil, and period, from 2004 to 2016.

For the international review, the platform used was Web of Science, due to its interdisciplinary profile, to its breadth of indexing scope and for being endorsed by Unicamp, the university where this review took place. The following keywords were used: EVALUATION and MENTAL HEALTH. Using the following filters: full text available, English, Portuguese and Spanish languages, and year of publication from 2004 to 2016.

We formulate the following text inclusion criteria: evaluation of a service or specialized program in mental health made by users, from different aspects such as satisfaction with the service, narratives of experiences for evaluation purposes, participation in the construction of the evaluation process as an interviewer and methods of analysis.

The text exclusion criteria were: services that were not exclusive to mental health, children's mental health services, specific interventions that did not evaluate the service as a whole, validation of instruments, users

did not participate in the evaluation, and other interest groups that did not include users.

After the first stage of this review, we set up the data analysis team, composed of three researchers in the field of mental health and public health. This is necessary during the process of selection, exclusion and analysis of the content of the selected texts, to avoid analysis bias, since the selected data underwent double evaluation between different members of the team to be eligible or excluded. If there was disagreement between two members regarding the inclusion or not of the text, a third broker would check and discuss with the team until reaching a consensus^(16,18-19).

From the platforms we found a total of 4,735 complete articles. It can immediately be seen in the analysis in relation to the title, that the reviewers selected 394 articles out of the 4,735. This was mainly because the titles already described the exclusion criteria listed earlier because they did not contribute to the objective of this study. Most articles were about medication evaluation processes, some specific practices and quality of life after brief interventions, without characterizing service evaluation. We also found a large number of surveys that heard only part of the interested parties, mostly service workers.

The 394 selected texts were systematized based on the following information: name of the evaluator, inclusion or exclusion evaluation, article title, year, keywords, authors, methods used in relation to user participation, type of service evaluated, country where the research was carried out, techniques used, found results, and observations relevant and electronic address of the text.

Then reading the abstracts reduced our sample to 137 articles. For this reason, it was possible to identify articles that only described and evaluated part of the good practices incorporated into the services and treatments provided. It was at this stage that most Brazilian and United States articles were excluded, as they did not address the objectives of this review.

Keeping the methodology, two evaluators analyzed the 137 articles in full and issued their judgment on whether or not to be included in the final analysis process. At this stage, there were no differences in most articles, with only 3 of them needing the third assessment. Thereby, we come to the 44 articles that clarify the objectives of this article.

Figure 1 illustrates the steps and numerical findings of the literature review in a flowchart format:

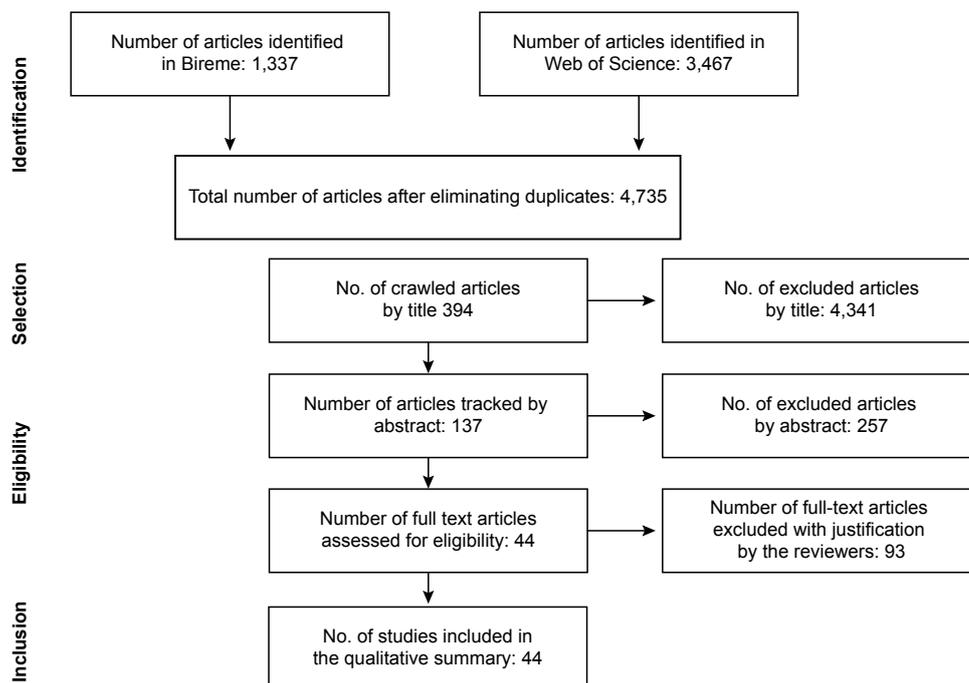


Figure 1- Flowchart of the bibliographic review

We know that in the Brazilian context the users' participation as collaborators and leaders in evaluation and research is incipient, and internationally only a few countries have adopted such practices^(11,20). Therefore, from the studied literature, we built categories to analyze the methods used in relation to user participation, considering four possibilities subdivided as follows^(11,20):

A1: The user's perspective is taken in 'third person'; users are subjects of research and the methods applied are mainly questionnaires and other closed instruments;

A2: The user's perspective is taken in 'first person'; interviews and or narratives of user experiences with services;

B1: User perspective with their participation as an interviewer and/or evaluator in part of the process together with other non-user evaluators;

B2: User perspective with their participation in all phases of the evaluation, in the construction of the method and question to be evaluated that may or may not count on other actors.

Therefore, the articles selected for analysis were tabulated according to the categories described above. Throughout the course we use the Excel® for organizations and tabulation of the findings and synthesis of the sample and the Mendeley® it was used as a support and organization tool for the final material.

Results and Discussion

Table 1 shows the distributions of the 44 articles selected for the final analysis by year of publication, country of study, type of service and method of user participation.

Table 1 - Distribution of articles by frequency - year of publication, country, service and method of user participation

	n	%
Year of publication		
2004	2	4.5
2005	1	2.3
2006	7	15.9
2007	2	4.5
2008	6	13.6
2009	8	18.2
2010	5	11.4
2011	2	4.5
2012	5	11.4
2013	2	4.5
2014	3	6.8
2015	1	2.3
Country of Study		
Germany	1	2.3
Australia	8	18.2
Brazil	6	13.6
Canada	4	9.1
USA	6	13.6
Finland	1	2.3
England	9	20.5
Ireland	2	4.5
Israel	2	4.5
Italy	2	4.5
Sweden	3	6.8
Service Type		
PHC	8	18.2
Hospital	9	20.5
Service Network	2	4.5
Specialist services	25	56.8
User's participation method		
A1	18	40.9
A2	16	36.4
B1	6	13.6
More than one method	4	9.1

It is noticed that there is no homogeneous distribution and so little growing over the years, since in 2009 we have the largest number of articles found, followed by the years 2006 and 2008, with 21 articles produced in these three periods.

In relation to the countries that have the highest production of articles on service evaluation that incorporate users in the process, we highlight England, Australia, United States followed by Brazil and Canada.

It is worth mentioning that England, Australia and Canada are countries with an evaluative culture of services, with national public health systems, which go beyond epidemiological data and public management reports, thus dedicating part of the evaluation studies from the perspective of the users/clients of the system^(11,14). Satisfaction surveys on access, treatment and conditions of services are common, using participatory methods and tools that include the different actors involved.

The United States, on the other hand, has a tradition of evaluating state-funded programs, since a good part of mental health depends on this type of financing to serve the population and there is no single national system^(11,14). We excluded several articles that were limited to just one practice, evaluation of drug responses, or to a specific audience identified by their diagnosis receiving timely treatment.

Brazil appears with six articles, which, compared to the countries previously mentioned, seems to be a good result, since the production of general evaluation of services stands out, considering the importance of the users in this process. The evaluation of services in Brazil is still a major challenge^(14,21). We know that there is a great effort by Brazilian researchers to create instruments, techniques, indicators and guides to good practices for the global evaluation of services with the participation of the users and other actors, but the practical results of systematic evaluations are not yet in the form of indexed articles on the studied bases.

As we expected, there is a great investment in understanding how users and other actors evaluate specialized services (25 of the 44 articles found), to the detriment of hospitals (psychiatric, university and nursing hospitals), considering the international movement, which includes Brazil, from reformulation of the mental health care model.

Specialized services are related to the treatment of people with severe mental disorder, alcohol and other drugs, housing or specific population (e. g., war veterans in the United States have an exclusive network). In Primary Care, they incorporate prevention and call center work. It is worth noting that we found two articles that evaluated two or more types of services concurrently (service network) and included users.

Most of the findings were concentrated in categories A1 (18 articles) and A2 (16 articles) for evaluation. The articles in A1 were characterized by interviews, questionnaires that sought the most objective assessment of the services, considering little or nothing of the users' subjective aspects. Those who use already validated instruments are more expressive in international experiences.

A2 brought more open opinion interviews, experiences and evaluations that could highlight their experience and how they evaluated the process. With regard to the methodological approach by which service users participate as research subjects (B1), it seems that research has invested more in the narrative experiences of these people to evaluate services, with users interviewing users.

It is worth mentioning that we did not find any article that approached B2, and four articles used more than one method for evaluations.

After this descriptive presentation of the quantitative and bibliometric data, we highlight the qualitative analysis of the most recent articles with methods A1, A2, B1 and those that use more than one method for the participation and users' evaluation.

United States and England had 4 articles each selected in A1. We highlight a study⁽²²⁾ evaluation of mental health programs aimed at war veterans in the USA, using a quantitative cohort method, using telephone interviews as tools, with internationally validated instruments, with emphasis on the RSA (*recovery self-assessment*). The findings indicate that people with comorbidities evaluated the care and treatment programs better than people with less complex conditions. However, with regard to person-centered practices and personal recovery, the program was rated less by all participants in all age groups, thus highlighting the challenge of these programs to develop improvements in these aspects to ensure quality of life of war veterans⁽²²⁾.

We found three Brazilian articles in A1 category, in the years 2006, 2009 and 2012. These are studies that have worked only with users, with instruments or closed interviews, using quantitative analysis methods, two evaluating Psychosocial Care Center (*Centro de Atenção Psicossocial*, CAPS) and an outpatient clinic. In general, users were satisfied with the treatment and the new services provided⁽²³⁻²⁵⁾.

All the articles that we included in the A1 model started from exclusively quantitative methodologies and with corresponding analyzes through data measurement programs⁽²⁶⁻²⁸⁾. What varied was the following: ways for collecting data: multiple choice interviews or application of instruments with Likert-type scales^(22,29-32); the sample size and the number of participants (with more than

300 respondents, including workers, users and family members)^(27,33-35); the data collection technique, such as telephone interviews, self-administered instruments sent by letters, e-mails or arranged at the reception desk^(22,26,30,36).

This format of evaluative service research is able to capture and measure a larger number of data, generating a more general analysis of how the services have been providing care and how the actors involved evaluate the treatment and the consequences of this work. These assessments refer to measurements called 1st generation evaluative⁽³⁷⁾, in which the evaluator is a technician who must know how to build and use the instruments, and that any research/evaluation variable must be measured statistically⁽³⁷⁾.

In the A2 category we highlight a Swedish article⁽³⁸⁾ which studied only users with severe and persistent disorders, based on interviews about housing and living, what we usually call in Brazil as Therapeutic Home Services (THSs). The phenomenological-based study sought individual and collective consensus on the narratives produced, building a value judgment on living in THSs. It was possible to highlight positive points such as rest, security and privacy space, with support from other residents and staff; but also negative points like dependency, passivity and oppression by residents and staff. The study concludes jointly with the users that in order to have a less institutionalized housing, support must be directed towards the rehabilitation and recovery of all⁽³⁸⁾.

The other three Brazilian articles are in the A2 category⁽³⁹⁻⁴¹⁾. All evaluated the CAPS, from users and other actors, using focus groups, open interviews and one of them used SATIS – BR scale⁽⁴⁰⁾. Data analysis was performed using quantitative and qualitative methods, using the hermeneutic cycle in the process of collecting and interpreting data^(39,41).

In the three articles, the CAPS were well evaluated in relation to the therapeutic practices employed, the reception of the crisis and the free treatment. Negative points are highlighted by the lack of inputs, measurements, precarious building infrastructure and difficulty in integrating with other points in the social assistance network. They indicate the permanent evaluation of services, as well as the importance of promoting citizenship, social and family participation processes as a support and citizenship network, in guaranteeing the users' rights⁽³⁹⁻⁴¹⁾.

We highlight the work⁽⁴⁰⁾ that evaluated a CAPS-type service in Rio Grande do Sul, using a qualitative method, with focus group techniques and hermeneutic analysis in the construction of consensus. Workers, users and family members participated, who were able to discuss positive points and challenges for the services,

which touch the contractual power of the subjects in their daily treatment.

In the A2 category, most articles worked using qualitative methods with techniques, such as: semi-structured interviews, narratives and focus groups⁽⁴²⁾. Only two articles were based on mixed methods⁽⁴³⁻⁴⁴⁾. It is worth mentioning that during the analysis of the data, the authors reinforce their theoretical frameworks for this, with emphasis on phenomenology and historical materialism, which we do not find in articles classified as A1.

The A2 category can fit the 2nd and 3rd generation assessment⁽³⁷⁾: the description (2nd), in which the focus is process, and not only in the measurement of results; the judgment (3rd), in which the appraiser also judges and issues opinions. Clearly, the articles sought the experience of people with the services and treatments received and how the different actors proposed changes in the process, but the analyzes still translate into narratives interpreted by the researchers⁽³⁷⁾.

In the B1 category, the four Australian articles⁽⁴⁵⁻⁴⁸⁾ caught our attention⁽⁴⁵⁻⁴⁸⁾ showing other forms of service evaluation that encourage greater participation by the involved actors.

One of the works⁽⁴⁵⁾ studied the users' perception on the services provided at different points in the Australian mental health network, with students and research users as interviewers. The interviews were semi-structured with a focus on discussing users' perception on the services. In general, users highlighted the lack of information during access to services, especially in hospitals, which made empowerment in the face of the situation being difficult. Still in relation to the hospital, they highlighted the negative effects of medications and the little dialogue with the doctors. The article also highlighted that health service evaluations should have the users' point of view at the center of the discussion, in order to contribute to more user-oriented practices and their recovery⁽⁴⁵⁾.

Another important difference was in the way users were involved in the research (interviewing researchers), which facilitated access to other users surveyed, with deeper reports during the interviews than those made by the students, indicating the relevance of this approach for assessing services. This research group argues that users can and should participate in other aspects of the research, seeking the depth of the evaluation process, generating data more reliable to the realities experienced, including questions that are really relevant for the users⁽⁴⁵⁻⁴⁶⁾.

The other two works⁽⁴⁷⁻⁴⁸⁾ discuss the evaluation process of primary care services in mental health in Australia, using qualitative methods with research users in focus groups, interviews and building consensual

narratives. The strengths of the results indicated for the evaluation of treatment received and supportive therapies and social connection. In relation to social connection, the importance of respect and support from peers was discussed as service offers for the recovery of the people. For some users, peer support was considered the most important and fundamental for their recovery and good evaluation of the services that indicated⁽⁴⁷⁻⁴⁸⁾. They also highlighted as important resources for the recovery and positive evaluation of services, drug treatment, plans and crisis management and spiritual therapies⁽⁴⁷⁻⁴⁸⁾.

Users discussed and brought negative ratings that deserve to be highlighted: the lack of employees and geographical barriers in Australian rural areas, unable to access services, with a delay of up to 4 days; lack of confidence in the teams and lack of systematization in the practice of peer support in these regions⁽⁴⁷⁻⁴⁸⁾. In large centers, the complaint was the feeling of being treated as numbers and symptoms and not as natural persons. They also highlighted the importance of expanding users' participation in the evaluation processes, from development to the analysis of more effective strategies for improving the services⁽⁴⁷⁻⁴⁸⁾.

The B1 category is perhaps the closest to 4th generation evaluations⁽³⁷⁾ through the methodological assumptions of the constructivist paradigm, in which the claims, concerns and questions of the interest groups serve as the organizational focus of the research and the information necessary for the analyzes. Thus, the actors or interest groups are involved or potentially affected by the service and by the eventual consequences of the evaluation process⁽³⁷⁾.

It is important to emphasize that users when participating in research tend to propose relevant questions, identify flaws in the research, are good indicators of the validity of certain protocols and instruments, offer interesting interpretations and follow the results⁽⁴⁹⁾. In Brazil, the literature on users' participation in academic research is limited, with experiences of inserting users in research being scarce and recent⁽⁵⁰⁾.

Countries like Australia and New Zealand have incorporated the participation of the users of Mental Health in research as their right. Research with more horizontal relationships between academic researchers and communities enables the professional development of academics, they tend to have greater credibility and user involvement in the adhesion of other peers to the research⁽⁵¹⁻⁵²⁾.

In relation to articles on evaluations that used various methods and ways of inserting users in the process, we highlight a study carried out in England⁽⁵³⁾, which used quantitative methods and statistical

analysis, as well as qualitative, with interviews, which were carried out by university students and users of the system, who had undergone hospitalization experiences. The challenges raised in the hospitals' evaluation process were the following: duties and dispositions of employees, ambience and communication, mainly related to rules and less to therapeutic processes, such as welcoming listening by the professionals. The users in the present study attached great importance to justice, being heard, having activities and being treated with respect⁽⁵³⁾.

Articles with multiple methods, with different forms of participation by users and other actors appear in more recent literature, starting in 2010, in countries with a strong tradition in systems assessment (England and Canada)⁽⁵³⁻⁵⁵⁾ and references in the reforms of the mental health care model (Italy)⁽⁵⁶⁾.

This presents itself to us as a major advance in evaluative culture, seeking to bridge the gap between quantitative Cartesian models and phenomenological, materialistic, historical and critical models. We consider it essential to use multiple methods, with the participation of as many stakeholders as possible, in different ways, for an evaluation of services that is truly committed to the affirmation of successful practices, as well as to the transformation of projects that do not serve the public at issue.

In the international articles, there is a greater number and investment in evaluation processes, even so the users' voice appears in lesser number in relation to workers and managers. The vast majority of articles evaluated only some conditions or practices of the services and the satisfaction of receiving that specific attention. Global assessments considering the service in its territorial and network complexity, with multiple offers and with diversification of methods and actors for the production of more consistent results are restricted. We highlight England, Australia, Canada, USA and Brazil with productions aimed at more global evaluations.

We know that there are other articles on the evaluation of mental health services in Brazil, however our finding corroborates with other reviews on the subject with different objectives^(8,57-58), in the sense that few studies give voice to users and, when they do, they only evaluate some practices and not the service as a whole.

Limitations

We expected to find more international articles valuing global assessments with all the involved actors. The fact that our analysis only contemplates productions that describe service evaluation and not specific practices, as well as the keywords that the authors used in the articles did not include those used

by us in the search (mental health and evaluation), may have influenced in our survey. Although we believe that the descriptors were quite comprehensive, they may not have captured any relevant article both nationally and internationally.

Conclusion

This article presented a qualitative systematic review of the literature on the evaluation of mental health services, highlighting those that incorporated user participation, identifying Brazilian and international national publications in the mental health area.

The quantitative data found showed us that Brazil has research on the evaluation of mental health services, but still in smaller numbers, in comparison with other countries like England, Australia and USA.

According to this review, the methodological approach of incorporating the user's perspective, that is, the way users are involved in studies, both in Brazil and in other countries, is still a challenge. There is little investment and efforts in building shared and effective research with the users' role.

We concluded from the results and analysis of our review on the importance of advancing in more robust assessments of mental health services, which highlight the voice and the users' participation, as they are still fewer in the world; and in Brazil, there is also the challenge of structuring systematic evaluations of public services, with a multiplicity of evaluation methods and involving all actors.

We considered that systematic review studies are always important tools for reflection to support research, illuminate phenomena and demonstrate how other researchers have studied the themes.

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